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Rowell, Jay

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Rescaling Disability: The Construction of a European Social Group and Policy Arena

Jay Rowell*

Abstract: »Behinderung redimensionieren: Die Konstruktion einer sozialen Gruppe und eines politischen Felds in Europa«. Control over the production, the circulation and the use of statistical knowledge is inextricably linked to bu-reaucratic forms of domination. The historiography of the building of the mod-ern State insists on the tight relationship between the capacity to collect and utilise statistical knowledge and the consolidation of bureaucratic domination. The creation of statistical categories symbolically unifies territories, social groups and practices. Similarly, the European Union has invested heavily in harmonising statistical categories, thereby providing institutions and actors with uniform descriptive languages. However, unlike statistical constructs of the Nation States of the 18th and 19th Centuries, European statistical catego-ries are generated in a context of pre-existing statistical categories structuring public policies and social practice and institutions. The article will be empirical-ly based on the emergence of EU disability policy which managed to carve out a new arena for policy discussion and coordination form the 1990s on. Although this policy does not imply a transfer of sovereignty, the statistical unifi-cation of this social group at the European level and the structuring of interest groups and expert groups can be interpreted as an exercise of rescaling which has transformed the definition of disability as a policy problem and operated a shift in resources and legitimacies among stakeholders. Despite the successful creation of a unified statistical category, the article will look into some reasons for the limited use of disability statistics in policy making, but then show how alliances put in place by the Commission with interest groups and expert circles institutionalised a new European sector for policy discussion.

Keywords: Rescaling, EU politics, policy sector, disability, sociology of knowledge, social policy.

1. Introduction

The European Union (EU), with its partial transfer of sovereignty, can be styl-ised as an incremental, but far-reaching project of rescaling which transforms

* Jay Rowell, CNRS, SAGE Research Centre, University of Strasbourg, 5 allée du Général Rouvillois, CS 50008, 67083 Strasbourg, France; jay.rowell@misha.fr.

national policy problems into common European problems requiring coordinated, if not common solutions. The legal principal of subsidiarity codifies the respective attributions of different levels of regulation implying a “natural” scale for the resolution of different types of policy problems. However, from a more sociological and constructivist perspective (Berger and Luckman 1966; Rowell and Mangenot 2010) it becomes clear that the existence of policy problems, the legitimacy of public regulation and the definition of the appropriate scale of their resolution depend on the mobilisation of policy entrepreneurs and the institutionalisation of common categories of observation and action (Penissat and Rowell 2015) which “make Europe” (Adler-Nissen and Kropp 2015). To better understand the rescaling of policy problems and target populations in the EU, we propose to take EU disability policy as an empirical example to identify the dynamics producing common categories, but also to point to the limits of an expert based process.

Until the mid-1990s and the relaunch of “social Europe”, the EU had not developed specific policies in relationship to disability. From 1996 onwards disability became the focus of increasing activity giving rise to a process of institutionalisation seeking to impose the EU as a new arena for policy making and coordination. A specific mention of handicap was included in Article 13 of the Treaty of Amsterdam of 1997 on discrimination; a “High Level Group on Disability” comprised of national representatives was put into place; in 1997, the European Commission funded and supported a peak organisation regrouping disability interest groups, the European Disability Forum and a dedicated unit within the Directorate-General for Employment and Social Affairs (hereafter DG Empl) was set up. In the late 1990s policy entrepreneurs in DG Empl, disability interest groups and, more peripherally, MEPs and experts from academia and think tanks seized the window of opportunity of the effervescence on social policy to promote the EU as a legitimate forum for policy relating to disability and impose the social integration of the disabled as a European public problem (Smith 2004).

1.1 Establishing a New Policy Arena in a Crowded Multi-Level Institutional Setting

The establishment of a new space of policy discussion and coordination did not occur in a vacuum. The World Health Organisation had made disability a significant issue since the 1970s and issued in 1981 the influential “social definition of handicap”¹ which marked a demedicalisation of the identification and

¹ In 1981 the WHO produced an influential integrated classification of disability by distinguishing between deficiencies, defined as a loss or an abnormality of a physiological, psychological or anatomical function; incapacity defined somewhat tautologically as an incapacitating limitation to accomplish activities considered to be normal for a human being

treatment of disability. Likewise, the UN has been active in the definition of rights of people with disability since its creation and issued a charter on disability rights in 2006. Even the economically oriented OECD has been active and has published a series of reports on jobs, education and health policies in their relation to disability (OECD 2003). However, the biggest challenge for the creation of a new policy arena at the European level was the variety of preexisting definitions, linguistic categories (Barbier 2008), institutional arrangements and levels of policy implementation in EU member States. The rescaling of disability at the European level over the past twenty years therefore took place in a dynamic context in which the issue not only cut across a variety of policy sectors (health, education, employment, housing, urban planning, human rights, care, fiscal policy...) but was also effected simultaneously by a downscaling trend through the decentralisation of the provision of services to local or regional governments, and a dynamic of upscaling through the activity of international organisations (Priestly 2007).

As in other social policy domains, EU member States have jealously guarded ultimate sovereignty, but the emergence of an EU arena and the highly visible role of stakeholder groups have reconfigured networks of specialised actors and display the main features of multilevel governance (Hooghe and Marks 2001). This includes a vertical intermeshing of policy fields facilitating the circulation of norms and categories and creating forms of interdependence necessary to the coordination of a variety of levels of government; the adjustment of problem definitions and solutions to the appropriate level of their resolution; the circulation of norms and resources; and the recasting of relationships between public actors and stakeholders. While the multilevel governance framework can be useful to conceptualise and to describe the imbrication of different levels of government, it has several blind spots which we would like to discuss in this article and confront with our case study.

First, in this framework, the existence of multiple levels of government co-operating in a given policy area is taken as a given, and does not first ask how new levels of government are carved out and successfully stake a claim on policy competencies where none had existed before. Governments and bureaucracies are structurally predisposed to defend their budgets and regulatory powers and so the ability of the EU to become a legitimate player in the field of disability cannot be taken for granted. Second, and in line with the first argument, different levels of government may be interdependent and may cooperate, but there are constant struggles for power and legitimacy over the definition of the policy problem in a way most favourable to the institutional interests of each collective actor. This involves competition for authority and resources

resulting from a deficiency; and handicap as a social disadvantage resulting from an incapacity hindering activities considered to be normal for a person of a determined age, gender, culture or social situation (ILO 1998, 16; CEC 2004, 24).

which often gravitate around the definition of problems, target populations, and solutions corresponding to the political and administrative goals and scales of intervention of each player (Schneider and Ingram 1993). Finally, the multi-level governance framework implies a general agreement on the nature of the policy problem, its scale(s), and the appropriate courses of action. Again, the creation of a new European arena invites us to study multi-level policy sectors as arenas in which actors compete to impose their viewpoints, and thereby study processes of monopolisation of authority and the conditions of a successful imposition of problem definitions (Georgakakis and Rowell 2013).

1.2 A Constructivist Approach to Studying the Institutionalisation of New Scales of Action

The relative success of EU Commission allied with Disability interest groups and experts in academia and consulting firms in carving out a policy space in a crowded institutional context therefore raises the question of resource mobilisation and problem framing (Snow et al. 1986). In many ways, the construction of the European polity can be usefully studied by drawing on literature on the role of knowledge management in the formation and consolidation of modern States (Desrosières 1998; Mespoulet 2008; Tooze 1996). The affirmation of a new center of administrative domination over a given territory requires a symbolic unification of the infinite diversity of situations, people, things and processes into homogeneous categories (Bourdieu 1993). In other words bureaucratic domination requires the translation of heterogeneous objects into homogenous categories, thereby making social dynamics less opaque and more predictable for government (Scott 1998) by embedding these categories into policy instruments (Lascoumes and Le Galès 2007). However, contrary to the dynamics of State building in the 18th and 19th centuries, EU actors seeking to promote a disability agenda were working in a context where member States had already constructed very resilient, but highly diverse categories.

The first section of the paper will therefore provide a brief overview of the preexisting diversity of disability policy and the categorisation of the disabled in member States. The historical sedimentation of very heterogeneous policies and categories built into welfare schemes provided a serious challenge to the construction of European categories and problem definitions. However, from the late 1980s on, one can identify a convergence in preoccupations in member States around the rising costs of disability benefit payments and labour market de commodification which created the preconditions for an upscaling to the European level of a shared problem definition. It was precisely the claim that member States faced common problems, but implemented very different policies for widely differing outcomes that constituted the discursive lever used by policy entrepreneurs in the EU Commission to justify a European rescaling of the “problem” of disability.

We will subsequently examine the process of sifting and sorting of preexisting policies which resulted in a problem definition focusing on employment. In other words, in the late 1990s, the problem definition was adapted to the emerging EU frame of employment as the flagship social policy signifying the exclusion or the subordination of a series of other policy objectives such as workplace safety, care, rehabilitation, poverty or housing. However, most importantly, the legitimacy of the policy frame and the European scale depended on the marshaling of evidence (Baumgartner and Jones 2005) taking the shape of statistical indicators embedded in causal stories (Stone 1989) and the outsourcing of expertise to academics and consultancy firms.

Finally, the European Commission did not just mobilise evidence to weigh both on internal battles and the opinions of stakeholders on the legitimacy and pertinence of the EU as a policy forum. It actively created and supported a coalition of allies in a relationship of mutual, if asymmetric interdependence with a network of academic experts, think tanks and interest groups. Thus, beyond the symbolic, legal and statistical unification of disabled Europeans, the institutionalisation of a European scale of public action also involved a deliberate strategy to structure a social and institutional space of actors with a direct interest in promoting and relaying a European frame and scale of public action.

2. National Specificities and Common Problems: Justifying a Common Approach to Disability Policies

The promotion of policies fostering the social integration of a vulnerable social group regarded as highly deserving of public solidarity (Van Oorschot 2006) appeared to be an attractive and consensual move to help humanise the image of the EU and demonstrate concern for the problems of ordinary citizens. As one high civil servant in DG Empl put it in an interview in 2007, “Who could possibly be against a policy to improve the lives of the disabled?” If there is a widespread consensus on the moral requirement for public action to support the disabled similar to the moral imperative to reduce traffic fatalities or fight cancer, disability is both a social and a policy category which has given rise to very diverse definitions and policies in member States. Therefore, beyond the general consensus on the deservingness of the disabled, the delivery of public action and even the definitions and perceptions of disability varied a great deal from one member State to another.

2.1 Conceptions of Disability Embedded in National Histories and Social Policy Arrangements

To begin, the semantic field of disability is highly fragmented both within nation states and between them despite the longstanding efforts of the United

Nations in diffusing legal definitions and the WHO in diffusing social or medical definitions (see note 1). In English, disability and handicap are two separate words united into one word in French and German.² Associated terms of the semantic field such as deficiency, incapacity, invalidity, infirmity or chronic illness convey a variety of implicit significations depending on the origin of the condition (linked to an accident, working conditions, congenital, lifestyle, illness...), the type of physiological impairment and the possibility of reeducation, rehabilitation or other forms of support. The term therefore covers a deviation from a social norm which is more or less pronounced, visible or only detected through a medical diagnosis, but its meaning in ordinary categories of language and perception depends on cultural contexts and the history of social policy.

The symbolic unification of the disabled and the institutionalisation of disability as a policy area was a gradual process linked to the development of social policies and the statistical apparatus (Kudlick 2003). For example, the US Census of 1888 produced a statistical and symbolic unification of the “defective classes” as a means to identify people with legitimate claims for government protection and distinguish them from the able-bodied poor (Fujiura and Rutkowski-Kmitta 2005, 72). The rise of biopolitics theorised by Foucault brought with it the constitution of knowledge based on the recording, measuring and comparing of populations around a statistical norm (Foucault 2003, 243). A diversified set of institutions and procedures sought to ensure the health and well-being of the population and to inculcate values and discipline to produce a subject complying with the requirements of capitalism (self-discipline, strength, independence, autonomy).

This general trend in the capitalist societies of the 18th and 19th centuries was refracted in many different ways, as disability policy was built into the specific configurations of social policies. In the United States, the premise of a Federal social policy began around incapacitated Civil War veterans, widows and orphans at the local and State level (Skocpol 1992). In Germany and France, initial social insurance policies sought to cover workplace accidents generating a disability making it impossible for workers to gain their livelihood (Ewald 1986). Modern disability policies were therefore often first constructed around a limited, yet highly legitimate population such as mutilated war veterans, handicapped children or victims of workplace accidents, but gradually expanded both in terms of recognition of new health risks and in terms of the spillover into a variety of policy sectors of the post 1945 Welfare State (education, employment, health, transportation, urbanism...).

² Henri-Jacques Stiker dates the semantic unification through the term handicap in France to the 1950s through a transfer from sports and betting terminology. Handicap condenses an anthropological conception of industrial capitalist societies which supposes the possibility to reeducate and rehabilitate the disabled, allowing them to enter the competition of the capitalist world by compensating for their disability (Stiker 2009).

The inscription of disability policy into social welfare systems generated a huge variety of programmes and measures. In some countries disability benefits are based on contributory schemes of salaried workers, while in others, policies are funded through general tax revenues or through subsidies to private insurance schemes. Some countries have mandatory employment quotas for the disabled (with or without sanctions) while others don't. Since the 1990s some countries such as the United States and the UK have focused on anti-discrimination laws and jurisprudence. Levels of support varied greatly as did policies to promote mobility, education or public health. This diversity can be read through the list of the ministerial affiliations of the High Level Group on Disability set up by the European Commission in 1996 which included representatives of the ministry of Justice (Ireland), Social Affairs (Italy, Denmark), the Family (Luxembourg), Health and Sports (Holland), Work, Health and Social Affairs (Austria), Work and Social Affairs (Germany), Health and Social Affairs (Finland and Sweden), Education and Employment (UK) and so forth.

Contrary to other collective and individual risks where the status of beneficiaries of public solidarity are identified through a set of relatively consensual and parsimonious criteria such as age, revenue, maternity or social contributions, disability appears as a more open and indeterminate category (Zola 1993). Obtaining official recognition as a disabled person requires submitting oneself to a set of examinations and evaluations by official gatekeepers such as doctors, social workers or committees in a procedure which can be seen as stigmatising. This results in a situation in which in most national contexts a high percentage of eligible persons do not claim benefits they are entitled to. Conversely, about half of the disabled of working age in EU countries are active in the workplace. The category therefore has fuzzy borders with great discrepancies from one country to another as definitions, identification procedures and forms of public support vary widely, thereby making the “empirical verification of the existence of distinct social borders of the group targeted by public policy” (Schneider and Ingram 1993, 335) difficult to establish at the European level.

2.2 The Cost of Disability: A Common Preoccupation of the 1990s

Despite these variations in institutional arrangements and definitions, the 1990s were marked by a rising awareness in most countries of the spectacular increase in the number of beneficiaries on disability benefits and spiralling costs in a context where budget deficits and the financial sustainability of social welfare systems became important concerns in national and international political spaces. The number of workers on disability benefit increased by an average of 40% in OECD countries in the 1980s and 1990s (OECD 2003, 61). This rise can be linked to two dynamics. First, social mobilisations and developments in medical knowledge increased the number of “invisible” medical conditions justifying workplace decommmodification: back pain, chronic muscular-skeletal pain, de-

pression or other mental illnesses. Second, profound economic transformations linked to the sharp decline of manufacturing, increased outsourcing and structural unemployment exerted pressure to remove workers with health issues and skills in low demand from the labour market (Alcock et al. 2003).

With unemployment being the central political issue in most European countries since the 1980s, the rapid expansion of disability benefits was initially considered a secondary issue until the 1990s brought stricter budgetary discipline in the run-up to the Euro and rising awareness of costs or early retirement schemes and the shifting of unemployed workers onto disability benefit. In most countries, disability benefits cost more than unemployment benefits and in the UK, the numbers rose from 570.000 in 1981 to nearly 3 million in 1999, more than double the officially registered unemployed (Clasen et al. 2006, 139). According to official statistics, Norway spent twelve times as much on disability as on unemployment benefits (Marin, Prinz and Queisser 2004, 20) and in the United States the number of beneficiaries rose by 43% in the 1990s despite a buoyant job market (OECD 2003, 61).

As a result, throughout the 1990s, most European countries introduced a series of measures to restrict access to benefits through more rigorous medical screening, reduced, capped or means-testing benefits and the introduction of requirements to accept retraining and employment outside their profession. Holland, often cited as a model for reform by the EU was one of the first countries to reduce benefit payments in 1993, the oblige disabled workers to accept employment compatible with their condition in any profession (1993) and transfer disability insurance to employers or private insurance in 1996 (De Jong 2004). In the UK, attempts to curb spiralling costs were introduced in 1996 with measures to establish a clearer border between the “truly” disabled and the “disguised” unemployed. Despite these various reforms and a relatively buoyant job market in the 1990s, the number of beneficiaries and expenditures continued to rise, while workplace participation stagnated or even declined in most countries (McVicar 2008; Burkhauser and Stapleton 2003, 10). The much studied and celebrated Dutch reforms managed to reduce public expenditure (from 4% of GDP in 1995 and 2.5% in 2005) but at the cost of reducing household incomes by 25% and with no effect on the number of registered disabled persons or employment levels (De Jong 2004, 182).

By the mid-1990s, the budgetary cost of disability had become a subject of preoccupation in most member States, therefore providing the preconditions for the requalification of disability as a common European policy problem and generating increasing interest in national bureaucracies for policy reforms in neighbouring countries. Although the heterogeneity of policies, definitions and levels of spending were cast as an obstacle to EU harmonization, initial EU Commission policy documents insisted on the existence of a common European problem and placed emphasis on the heterogeneity of policy outcomes to justify policy harmonisation as a path to greater efficiency and a way to guarantee the

equal treatment of all (disabled) European citizens regardless of nationality. Rather than downplaying national differences, initial policy documents actually drew attention to the most stark differences, pointing out for example that the percentage of adults of working age on disability or long term illness benefits oscillated between 4% and 12% in member States, that the number of registered disabled persons varied between 4.6% in Italy and 29% in Austria, and that public expenditure varied between 0.7% et 4.6% of GDP (Eurostat 2001). If these figures raise enormous methodological problems, they provided powerful justifications for upscaling. However, the construction of a European arena for disability required the search for common ground in two areas: the first consisted in identifying a set of common policy problems more politically palatable than simply saving money; the second required the construction of common categories of observation and action to set policy objectives and compare and evaluate outcomes.

3. Sifting, Sorting and Rescaling Categories of Observation and Action

The first official EU publication on the subject was the 1996 report of the “High Level Group” of national representatives whose objective was to “review current developments in existing policies in member States and bring together information and experience” (CEC 1996, 1). This document was a first step in the process of sorting through the myriad of existing policies at the national level to identify common ground for cooperation at the European scale. The document identifies five “spheres of exclusion” in which “a significant number of [disabled] citizens don’t have the same access to rights and opportunities as the majority of citizens”: education, employment, mobility, housing and poverty (CEC 1996, 2-3). This first document is interesting in several ways. First, it reflects the fact that disability is inscribed into a number of policy sectors and ministries. Second, the question of health and the prevention of long-term illness remained outside of the scope of the report, which is a surprise at first glance given that the history of disability and its definitions were for many decades dominated by medical knowledge and a rehabilitation and prevention frame in most countries. Third, the theme of discrimination and legal approaches are absent from the document, even if Ireland and the UK had recently voted anti-discrimination legislation modelled on the Americans with the Disabilities Act of 1990. Finally, even if employment figures in the document, it is far from occupying the central place that it would subsequently hold. How was it then that within two years, European disability policy would become nearly synonymous with employment policy to the near total exclusion of the four other “spheres of exclusion” identified in 1996?

3.1 The Centrality of the EU Commission as a Policy Entrepreneur

To understand this process, it is important to highlight that the High Level Group directly met infrequently and was marked by a turnover of the members delegated to the meetings by their national ministries (Interview civil servant, DG Empl, December 12, 2008). Between meetings, the civil servants of DG Employment played a decisive role in setting the agenda for the meetings, drafting documents and independently publishing a series of working papers and documents which became increasingly focused on employment, a policy which was taking shape as the flagship policy for the renewal of EU social policy from 1996 onwards. In successive documents produced by Commission civil servants identifying key problems and sketching out the contours of a desirable European policy model, the themes of health, education, housing or poverty were progressively marginalised. Economic integration of the disabled was seen as the cornerstone to solving all other difficulties affecting their lives (SEC 1998, 1). The shared problem identified was therefore not poverty, discrimination or insufficient access to social services, but low labour market participation generating poverty and social exclusion. A 1998 staff working paper identified the Commission as the most adequate coordinating actor to improve well-meaning, but misguided, national policies through a change of scale.

Given the scale of the problem and the effort required, member States have become aware of the necessity to rethink action in this policy sector. The problem of the multiple barriers that confront disabled people on the employment market demonstrates the necessity to adopt a global response to meet the challenges. Member States wish to increase activity rates of disabled people by encouraging them to move from welfare to work by eliminating the many obstacles to their full participation. (SEC 1998, 2)

The policy papers produced by DG Employment between 1997 and 2000 gradually transform the means (employment) to achieving social inclusion into the sole policy objective and a lever to encourage far-reaching reforms of welfare provision in member States. In doing so, the Commission positioned itself as the champions of the interests of European disabled persons but also of the overarching interests of member States:

In addition to a particularly low rate of employment, member States indicate that a majority of disabled persons of working age are far removed from the labour market and highly dependent on benefits. These benefits often reinforce market exclusion by creating an inactivity trap [...] [*the situation can be improved by*] moving to a culture of work and fighting the culture of dependency by removing the barriers to full social participation [...] and rethinking and reforming benefits systems. (CEC 1997, 2)

Commission documents harness the image of the disabled produced by European interest groups such as the European Disability Forum or Workability Europe insisting on *abilities* rather than handicap by implicitly assuming that all disabled persons were capable of productive work given the proper support

and incentives. Existing “passive” policy measures such as benefits were portrayed as well-meaning, but inefficient and even counterproductive by stigmatising, creating disincentives and promoting a “culture of dependency.” A 1998 DG Employment working paper pleaded in favour of “a common frame of reference for future action by member States to reach the targets of their employment strategies including the improvement of employment opportunities for people with disability” (SEC 1998, 1). For the next ten years, the Commission would constantly repeat the same message around the necessity to replace policies which “compensate a state of social exclusion” with “measures that promote social and economic integration” (CEC 1997, 11). What was missing was empirical evidence on the scope of the problem and the identification of “best practice” which could be generalised as the basis for a common European policy.

3.2 Marshalling Evidence: The Statistical Construction of a European Social Group

Largely insulated from electoral pressures, the internal working of the EU commission places a premium on apolitical forms of interaction largely based on a transformation of political issues into questions mobilising expertise. The challenge thus facing policy entrepreneurs in DG Empl was conforming to the imperative of “evidence based policy making” largely based on quantitative reasoning. As a result, DG Empl, via Eurostat, invested heavily in refining the statistical apparatus measuring disability and its relationship to labour market participation. The underlying objective was to identify countries with the best performance in order to establish causal links between outcomes and policies as a means to identify best practice that could in turn serve policy convergence. However, the task of quantifying a group as heterogeneous as the disabled proved to be daunting. Already a difficult problem at the national level due to the fluid boundaries between the “able bodied” and the disabled, the problem was compounded at the European level by incommensurable national statistical categories. Given this extreme disparity of national administrative registers, the decision was taken to include or refine indicators on impairment in two flagship Eurostat surveys: the Labour Force Survey (LFS) and the EU Survey on Income and Living Conditions (EU-SILC).

While the phrasing of the question varied slightly, both surveys sought to measure impairment and its effects by first asking respondents if they had experienced a chronic medical condition over the past 6 months, then went on to ask if this condition hindered them in the accomplishment of a series of daily activities (in the case of EU-SILC), or the type or quantity of work (in the case of the LFS). While the phrasing of the question in the EU-SILC and the inclusion of all age groups produced a higher overall estimation of disabled persons in Europe, the Commission chose the figures from the LFS (limited to persons of working age) in policy documents and statistical analysis. The number gen-

erated by LFS was nonetheless dramatic and became the starting point of all policy documents of the EU as well as European interest groups: 44.6 million Europeans were presented as disabled in 2002 (16% of the EU population), a number which jumped to 80 million following EU enlargement and definitional changes. While the choice of LFS was in part dictated by the revision of EU-SILC at the beginning of the 2000s which did not allow the disability module to be included in all national surveys, LFS was better equipped to produce statistics on the central aim of policy: employment. This facilitated the production of statistical knowledge on labour force participation, educational levels, age and gender, but simultaneously created several important blind spots which the use of EU-SILC would have brought into view. First, by focusing on the working-age population, forms of impairment linked to ageing and affecting children were invisible. Second, contrary to EU-SILC, the LFS did not measure income levels, sources of income, poverty or housing conditions which were outside the policy frame, but which could be construed as essential to the measurement of social inclusion. Finally, LFS did not go into any detail on the origins of the impairment (congenital, chronic illness, accident, etc.) or the type of impairment (mental, sensorial, muscular-skeletal, cardio-vascular, etc.). The production of a single number of disabled Europeans symbolically united a new European social category harnessing the social and political authority of numbers. By grouping together individuals of different nationalities suffering from a very wide range of impairments and with very different perceptions of incapacity (over a third of self-declared sufferers of a chronic illness reported no limitations in the amount or type of work they could accomplish), the statistical construction of the disabled was abstract, decontextualised, and in many ways a-sociological. While this was not a problem in communicating to the general public, statistics on disability and labour participation failed to provide convincing evidence for robust policy making.

3.3 The Fragility of Survey Based Statistical Knowledge

When compared to beliefs in macroeconomic data or microeconomic modelling, beliefs in the ability of social statistics to accurately measure reality are hampered by a series of structural obstacles. Contrary to macroeconomic indicators they have not been the object of decades of standardisation and widespread use. In addition, they often rely on survey research based on (subjective) self-declaration rather than supposedly more objective reporting from administrations or economic actors. EU civil servants specialised in employment are most often trained economists and so naturally question the credibility of data “based on some sort of subjective self-declaration” (Interview Unit head, DG Empl, April 18, 2008). In addition, the overall figure of 16% of the working age population masked huge national discrepancies between national samples despite the care taken in the translation and formulation of questions. The distribution around

the European average of 16% ranged from 6% to 32%, a difference which could not be explained through demographic or public health differences (Ward and Grammenos 2007, 20). In other words, standardised survey data which sought to get around the problems of incommensurable national administrative records continued to reflect cultural and linguistic differences with regard to health norms, acceptance of disability or social stigma attached to incapacity, thereby weakening beliefs that they “objectively” measured disability.

Furthermore, no clear patterns emerged from data analysis linking positive employment outcomes to the types of “active” policies promoted by the Commission. Following the issuing in 2001 of the Lisbon target seeking to bring activity levels in the EU from 62% to 70% by 2010, statistical analysis and benchmarking on labour participation rates allowed for the identification of “targets for activation”: women, workers between 55 and 64, young workers, and the disabled. Disabled workers were designated as a “labour reserve” and an “exploited potential for activation” (CEC 2006, 73). LFS data was harnessed to justify claims that increased activity rates would not only be key to promoting social inclusion, but that active policy targeted to the disabled would contribute to economic growth, reduce public expenditures and make a significant contribution to the overall Lisbon labour market targets (CEC 2005, 2-3). A 2002 DG Empl document went even so far as strive to “bring the percentage of disabled persons in work to the same level as the non-disabled by 2010” (CEC 2002, 7). This goal meant reversing, in a short time span, a structural problem (LFS estimated that 42% of disabled Europeans aged 16-64 were working) for a population that was on average older, less educated and suffering from health problems.

While most publically available Commission documents generally avoided providing quantified targets, one staff working paper and two papers commissioned to external experts identify a potential for “activation” at between 3 and 8 million Europeans. Interviews with personnel from Directorate-General Economic and Financial Affairs (hereafter DG ECFIN) indeed demonstrate that DG Empl officials made claims of this sort in internal discussions in an attempt to draw more attention and resources to disability:

Any contribution to increasing activity rates is useful. If this comes from women, older workers, the disabled, it doesn't really matter. All that is positive, of course. But my feeling is, and this is my personal opinion, that they [DG Empl] had a tendency to go overboard, to say that the disabled could make a huge contribution... they were talking millions. Yes, they can contribute, but realistically, the disabled are not the biggest source of underutilisation of labour in Europe. So they had a tendency, according to me, to weaken their position by exaggerating too much. This type of argument can actually end up being self-defeating. (Interview Unit head, DG Ecfm, December 10, 2007)

An analysis of LFS data by a consulting firm in 2007 indeed demonstrated that people declaring a chronic health condition, but stating that the condition did not significantly limit the type or quantity of work they could perform actually had higher activity rates than people declaring no disability. It is only among

respondents declaring important effects on the quantity or type of work they could do (about a third of those declaring an impairment) that the “activity” gap became extremely significant (Grammanos and Ward 2007). Just as puzzling to Commission civil servants, the countries which were most often mentioned in interviews and singled out in policy papers for their “active” and innovative policies (Denmark, UK, Holland) actually performed quite poorly in terms of activity rates (both as percentages of those declaring a medical condition and in absolute terms), while countries with stigmatized “passive” policies or protected and highly subsidised employment schemes such as France or Germany actually had better outcomes. If the civil servants interviewed from DG Empl seemed unaware of this data, failed to grasp its meaning, or appeared to have made little use of the six lengthy reports commissioned between 2000 and 2004,³ civil servants from DG Ecfm probably had a more realistic and informed vision, allowing them to claim the high ground on an issue which was theoretically the “property” of DG Empl:

The economic argument they made is a double edged sword. If one makes a close analysis of all the available data on active labour market policies, if one really takes a close look at the economic or fiscal bottom line, it is sometimes better to just pay people to stay at home rather than to throw vast resources at the problem with a very limited result. (Interview Unit head, DG Ecfm, April 16, 2008)

DG Empl lost the internal battle of bureaucratic authority on control over employment policies around 2005 (Erhel 2011) and the framing of disability as a problem of work lost steam due to uncertainties over its measurement and when it became clear that the disabled were the only target group for “activation” where labour market participation was actually declining. By the late 2000s, policy objectives shifted to more traditional Community methods, in particular with anti-discrimination legislation. The Disability unit itself was transferred from DG Empl to DG Justice in 2011. The statistical apparatus continues to churn out data, and documents published by the Commission and interest groups continue to highlight the numbers of disabled Europeans, but the shift to a rights-based strategy means that statistical data is hardly used to formulate or justify European disability policy. The following question then arises: What was the purpose of the dozens of costly studies and reports and the statistical data so painstakingly gathered and analysed by consultants and academic experts?

³ We constructed a data set of 71 non-medical research projects funded by the EU between 1992 and 2012 and compiled a data base of 234 EU disability experts which also included the Academic Network of European Disability experts. In interviews with four members of the Disability unit in the late 2000s, none of this research was spontaneously cited as a resource for formulating policy. When directly asked which outside experts played a role, one economics professor was named. This professor based in Brussels was a personal relation of the civil servant questioned but was not among the 234 officially funded or recognised experts in the data set.

4. Creating a European Policy Community

Despite an employment approach to disability which failed to produce any tangible results, the policy area has survived as a European issue with its own administrative unit providing funding for research and social programs. The Commission continues to produce a steady stream of policy papers, “action plans” and “strategies.” To understand the survival of a policy area despite the failure of the policy it promoted, one can make the hypothesis that it was the ability of the Disability unit to structure a space of actors specialised in EU disability policy which produced lock-in effects making it possible for a policy community to outlive the policy it had promoted for a decade. Gravitating around the Commission one indeed finds two types of allied actors: academics and experts in consulting firms and think tanks on the one hand and federations of European disability interest groups on the other.

Recent research on the relationships between EU institutions and European studies (Rosamond 2015), legal studies (Vauchez and De Witte 2013), economics (Mudge and Vauchez 2012) or public opinion research (Aldrin 2011) have drawn attention to the solid structuring of European subfields based on reciprocal exchanges of resources, expertise and legitimacies (Robert 2012). It has also been noted that the creation of new European policies or administrative transformations reconfigure the structure of European interest groups (Courty and Michel 2013). These transactions forge a convergence of interests and representations further cemented by the circulation of actors between the Commission, academia, think tanks and interest groups or their multipositionality (Michel and Robert 2010).

4.1 Creating European Interest Groups from Scratch

Until 1996, EU disability policy was primarily administered through structural or social funds. The Commission funded local initiatives involving disability associations and private partners in areas such as improving the accessibility of public infrastructure, developing assistive technologies, training social workers or identifying best practice. In the run-up to the Amsterdam Treaty and the lobbying for the inclusion of the disabled in Article 13 on Equality and freedom from discrimination, DG Employment began to dedicate resources to encourage the emergence of European interest groups and peak organisations in the field of disability. Most European interest groups were indeed founded after 1996: European Disability Forum (1996), the largest in the field with a permanent staff of 10-15, got about 80% of its funding from the Commission (Granick 2010), the European Association of Service Providers for Persons with Disabilities (EASPD) founded in 1996, the European platform for rehabilitation (2001), Mental Health Europe, Inclusion Europe, or Workability Europe (2001), to name the most active groups.

In this configuration, the European Disability Forum (EDF) played a central role as peak organisation. The successive directors played a key role in public events organised by the Commission on the topic and often shared the floor during the most visible events alongside the EU Commissioner or Disability unit head. The first director of EDF, Nicola Bedlington, had worked in the 1990s as a contractual agent of the Commission in charge of outreach programmes to national disability associations, before heading the European Deaf Forum, one of the founding members of EDF, and then moving on to direct EDF at its inception in 1996.⁴ Another former director, Carlotta Bezozzi, holds a Masters in political science and international relations, was a parliamentary assistant at the European parliament between 1995 and 2000, then became policy officer at EDF in 2000 and director in 2004.

In the division of labour between the European interest groups, EDF with its 5 to 7 policy officers, maintains close contacts with relevant Commission officials, while the smaller federations, often with only one or two policy officers (who may be shared between two separate associations, who also often share office space), are only convened to discussions on more specific issues: the service directive for EASPD; mental health issues for Mental Health Europe, and so forth. The input of interest group representatives primarily consists in identifying potential obstacles to implementation in national settings on a proposed Commission measure. Their usefulness to the Commission therefore lies in their ability to gather information from a diversity of sectors and social contexts and to “translate, reformulate and illustrate potential problems which we can bring to the attention of the Commission” (Interview policy officer, European Platform for Rehabilitation, Brussels, May 4, 2009). This flow of information creates vertical linkages between European federations and national associations, but most vertical information exchanges consist in identifying and circulating “best practice” and in supporting national associations in obtaining European project funding (Interviews policy officers, EASPD and Workability Europe, May 7, 2009).

The proximity of Commission officials to European interest group representatives based on a circulation of personnel, subsidies, and reciprocal flows of information have generated a close relationship between the Commission and policy officers. European interest group professionals are often young holders of Masters in European studies who have had no prior experience in national associations or ties to activism. They are sociologically close to Commission officials, share a technical, denationalised and depoliticised style,

⁴ Nicola Bedlington holds a BA in management from the University of Manchester. After a brief period of employment at the Centre for Disability Studies at Leeds University which was central in establishing the field of Disability studies in Europe, Bedlington engaged in a European career and currently heads the European Patients Forum. Her homepage mentions her role as expert for the EU commission and her role as coordinator of an OECD network of experts on education and sustainable development.

which can create frictions with representatives of national associations with a background in activism (Interview policy officer, EDF, May 9, 2010). This dynamic, observable in other similar fields such as trade unions (Wagner 2013), tends to autonomise a European space of policy deliberation and distend links between interest group principals and their agents in Brussels. With regard to the labour activation frame, proximity between the Commission personnel and European interest professionals provided symbolic support, but did little to strengthen the hand of DG Empl in its struggle with DG Ecf. First, DG Empl was always suspected of being “captive of their clientele,” to use a recurrent expression used by interviewed DG Ecf officials when referring to their counterparts of DG Empl. Second, none of the interest group policy officers active in disability had a background in economics or quantitative social sciences. Their activities remained mainly cast in legal terms and centred on the legal obstacles of proposed measures in national settings, rather than knowledge production or analysis which could have been potentially useful in evaluating the impact of policy on activity rates. This type of discussion remained part of exchanges with national governments in the framework of the national employment strategies (NEP), but disability played a very marginal role in these reports and the production of the NEPs remained largely confined to ministerial bureaucracies. Interest group representatives therefore did little to relay knowledge claims, statistical data or EU policy recommendations towards their constituents, thereby hindering a wider social diffusion of the employment frame and objectives. The anti-discrimination frame adopted in the late 2000s was in the end both more in phase with legal approaches of advocacy groups and with the skills of European interest group professionals.

4.2 Institutionalising Disability Expertise

As demonstrated above, expertise outsourced to academics and consultancy firms had little resonance within DG Empl. One could have expected increased recourse to outside expertise in times of uncertainty, for example in the late 1990s in the search for tools to identify problem areas or to evaluate best practice or in the late 2000s to research the effects of anti-discrimination legislation in national settings, but we actually find just the opposite. The recourse to expertise funded by the Commission occurred after the officialisation of policy frames. Using the EU Cordis tool, we created a data base of 71 funded projects on disability (excluding strictly medical research) covering the period 1992 to 2012 and could establish that research on employment was only funded after 2000. Similarly, the first research contract on comparative legal approaches was commissioned in 2010, when the anti-discrimination frame was already firmly established. While the tendering of research undoubtedly helped to flesh out, operationalise, and legitimise policy preferences, we would like to insist here on the transactions which bound academic and non-academic experts to

the Commission, both sociologically and symbolically, and thereby contributed to reinforcing and broadening the field of actors with a direct interest in supporting a European scale of action on disability.

Academic publications comparing disability policy or law in European countries or taking EU disability policies as an object are marginal in Disability studies or their respective academic disciplines (primarily sociology, political science, and epidemiology). Significantly, the timing and intensity of scientific publications on these issues closely followed the institutional agenda of the EU and were clearly stimulated by European research funding. The leading authors of comparative and European disability studies have nearly without exception participated in research projects funded by the EU and participate in the network of experts set up by the EU (ANED) from 2007 onwards. The emergence of a subfield within disability studies with a comparative and European perspective, with its own scientific journal founded in 2007 (*ALTER – European Journal of Disability Studies* published by Elsevier) undoubtedly contributes to legitimate the existence of Europe as a scale of discussion on disability policy and outcomes. Academics active in this field were also in many cases “national experts” for the OCDE or the WHO or even worked for the OCDE during part of their career.

While academics publishing on European or comparative policies and doubling as experts all have distinguished careers, they are not the most recognised or quoted scholars in the field of Disability studies or in their discipline. The most central academics in this field, who were often at the forefront of the institutionalisation of Disability studies in the 1980s, combined academic and militant investments by promoting a radical constructivist scientific agenda, which was undoubtedly foreign to the more pragmatic needs of Commission officials less interested in a Foucauldian critique of the category itself, than applied research which could be mustered in identifying best practice and policy convergence.

At the end of 2007, the Commission funded and set up a permanent network of disability experts to replace the ad hoc tendering of reports, research and expertise. This corresponded with the shift towards a more legal based approach, reflected both by the profiles of the research themes and the academic profiles of the lead scholars. While the emphasis was placed on academic expertise, the European Disability Forum played a central role as did Human European Consultancy and the Centre for Disability Studies of Leeds University.

The careers of the leading figures of ANED of the 2010s demonstrate the importance of multipositioning in academia and European expertise. The lead academic of ANED, Mark Priestley, became director of ANED at age 44, just a year after obtaining a professorship and being named director of the Leeds Centre which played a leading role in the institutionalisation of Disability studies in the UK and Europe in the 1980s and 1990s. Author of three books, he publishes regularly, but his publications are limited to disability journals and not the most central journals of his discipline. As director of the Leeds Centre,

he commands a significant research potential and international research networks and has a long track record of being an expert. Lisa Waddington and Anna Lawson, both legal scholars who took on responsibilities in ANED in the late 2000s present similar profiles, but with more international career paths (PhD University Institute of Florence for Waddington⁵). A fourth central figure, the legal scholar Gerard Quinn, of the University of Galway, has a career more centrally focused on expertise: holder of a degree from Harvard Law School, Quinn had worked for a time for the European Commission and specialised in comparative law. With few academic publications, Quinn nonetheless multiplied institutional positions of expertise at the national level (Irish Human Rights Commission), in European arenas (ANED, Vice president of the European Committee for Social Rights – Council of Europe), international venues (member of the working group drafting the UN Charter on rights for people with disabilities), and private actors (expert for no less than seven private foundations or interest groups). The last two lead scholars of ANED, Jean-François Ravaud and Anne Waldschmidt, reflect a more pure academic and national profile, as they are leading figures in their national fields, and publish in prestigious journals of their discipline outside of disability studies, but are less active in international expert circles.⁶ These profiles, and other profiles of experts active in ANED which include Stephano Grammenos, an economist working for the Centre for European Social and Economic Policy, a European policy think tank, demonstrate that recognition as an expert is not purely based on academic credentials, but depends on institutional positions and a dense network of connections to interest groups and consultancy firms. These properties provide the Commission with guarantees in the capacity of academic experts to produce pragmatic, policy oriented recommendations detached from purely academic debates. The hybridisation of academic, expert and bureaucratic logics is visible through the individual biographies, but also through the organisation of ANED itself which closely associates EDF policy officers in the drafting of reports and the institutional knowhow of Human European Consultancy, a Dutch based firm, whose expertise closely followed the political preoccupations of the Commission in the field of social policy over more than two decades.⁷

⁵ Lisa Waddington is holder of a professorship at the University of Maastricht funded by EDF, which receives in turn the lion's share of its funding from the Commission. Her thesis, defended in 1993 was entitled: "More Disabled Than Others. The Employment of Disabled People within the European Community: An Analysis of Existing Measures and Proposals for Reform."

⁶ Jean-François Ravaud has directed since 2007 the research federation that hosts *ALTER-European Journal for Disability Research* whose chief editor was for several years Henri-Jacques Stiker, one of the leading figures in Disability studies in Europe.

⁷ Founded in 1986 by trade unionists of the Dutch public sector, the firm obtained its first European contract in 1992 on social policies in Hungary before going on to specialise in policy expertise in social and health policies in central Europe. At the end of the 1990s the

5. Conclusion

Over a decade, attempts by the EU to coax member States into focusing disability policies on labour market participation by promoting “active” policies based on statistical evidence appear to have largely failed. Similarly, the strategy based on a general and far reaching directive on discrimination which includes the disabled among other groups has remained bogged down by national opposition to the encroachment of EU law into sensitive national prerogatives. Paradoxically, this apparent policy failure to bear normative, cognitive or regulatory pressure on national decision-makers didn’t prevent the EU from succeeding, at least partly, in institutionalising the disabled as a European social group. While disability statistics failed to generate beliefs in their capacity to accurately measure incapacity and the effects of policy on different forms of social inclusion, the creation and diffusion of a global number relayed by the Commission, experts and interest groups instituted a new European social group. Likewise, in creating and supporting the creation of European federations of disability interest groups acting as officially recognized spokesmen and instituting the disabled as a legal category in treaties and directives, the Commission constructed an institutionalised category of European disabled persons. Enrolment of academics and consultants through targeted research funding and the support for a permanent network of European disability experts provided complementary forms of legitimacy for a European scale of observation and action. The Commission therefore appeared to be more successful as an institutional entrepreneur than as a policy entrepreneur. It managed to durably structure a space of European specialists composed of interest group representatives, academics and consultants which proved strong enough to resist the abandonment of the dominant problem frame, but too weakly connected to national policy spaces, and incapable of producing decisive evidence to support policy claims to bring about decisive transformations in the design of policy delivery at the national level. Can one conclude from the failure to produce output legitimacy in this policy field that the European arena of disability policy provides little more than a fig leaf of legitimacy for the EU in social policies?

One can argue that a primary effect of the focus on employment and activation may have been the exclusion of other possible problem constructions from the preoccupations of policy makers. Indeed, using the Labour Force Survey as a statistical basis for identifying problems excluded the possibility to produce knowledge on a series of issues which were present in 1996 policy documents but quickly disappeared: the high number of people with serious impairments

firm followed Commission priorities and provided expertise on discrimination and human rights in Eastern Europe, in particular the Roma minorities, but also on disability and other human rights issues in Eastern Europe in the run up to enlargement.

who don't claim disability status, benefits and support; the problem of poverty and adequate housing which was accentuated by reductions in benefits in the name of fighting "benefit traps"; the prevention of workplace accidents, limiting exposure to dangerous substances or support public health policies seeking to reduce debilitating illnesses or accidents. Furthermore, the emphasis on employability, activation, and "benefit traps" constructed the disabled as utility maximisers and policy as a tool to "help people make the right choices" (Interview civil servant, DG Empl, December 12, 2008). The universal and abstract "unit" of the more or less employable (or disabled) individual overshadowed other sociological characteristics of this population such as the strong correlation with age, blue collar professions and low educational attainment. With statistical indicators centred on the individual, the actual functioning of labour markets have remained largely outside the field of vision and these are all issues which an eventual anti-discrimination directive, no matter how ambitious, are unlikely to address, if the predominantly negative effects of the Americans with disability act of 1990 on employment levels are any indication (Burkhauser and Stapleton 2003).

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